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ABSTRACT

Designed for Massachusetts parents and adolescents with special health needs, this booklet provides information on the transition to adulthood. It covers four major areas of adulthood: health care, education, employment, and recreation. It includes: (1) a family fact sheet on health care transition that explains important issues and lists practical steps that should be addressed in adolescence; (2) information for adolescents on becoming their own health care advocates; (3) tips for creating an effective educational transition plan; (4) information for adolescents on taking charge of their education; (5) suggestions for planning for employment; (6) information for adolescents on preparing for a job; (7) tips for creating rewarding recreational experiences; (8) information for adolescents on making friends, enjoying recreation in their community, and having fun at home; (9) Internet resources on transition; (10) suggestions for communicating with doctors and other health care providers; (11) a checklist for planning for education after high school; (12) potential consultants to the transition team; (13) agency resources relating to transition planning; (14) Massachusetts state resources; (15) information on Social Security Income work incentives; (16) a checklist for planning for employment; and (17) a summary of the laws related to adolescent transition. (Contains 31 references.) (CR)

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Transition Planning for Adolescents with Special Health Care Needs and Disabilities:

Information for Families and Teens

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Transition Planning for Adolescents with Special Health Care Needs and Disabilities: Information for Families and Teens

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September 2000

Produced by the Institute for Community Inclusion/UAP at Children's Hospital, Boston, as part of the Massachusetts Initiative for Youth with Disabilities, a project of the Massachusetts Department of Public Health. Supported in part by project #H01MC00006 from the Maternal and Child Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

Dear Families and Teens,

The journey to adulthood for a child with special health care needs or disability is filled with joys and challenges – as it is for any child – just more so. From the day the special health care need is known and onward, family members must learn new vocabulary, new techniques and procedures. They meet doctors and other health providers they may never have known even existed. They learn about and become connected to organizations, programs and people in their community whose path they had never crossed before. They even learn about laws unknown to them earlier.

Life can become more than busy as families work to get the best for all their members. As these full days unfold, our children are entering their adulthood – an adulthood that should offer them the opportunities, pleasures, and challenges available to anyone.

This booklet has been developed for families to help you prepare together for adulthood. Just as families have had to spend more than the average amount of time attending to their young child's care, the transition to adulthood will be best accomplished if families devote extra effort and energy to that transition. This booklet has been written to help and guide you – to give you the information, ideas, tools, and resources you need along the way.

The booklet covers four major areas of adulthood:

- Health care
- Education
- Employment and
- Recreation

There is information for parents and especially for teens. Review it together and individually and keep it handy for frequent use. Adulthood does not happen overnight, nor does preparing for adulthood. We recommend that you work together starting when your child is 14 years old.

Good luck and enjoy the journey!

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25... Planning for Education after High School (A guide to assist in thinking about student needs and action steps to meet the stated needs)

26... Potential Consultants to the Transition Team (A list to share with adolescents, families and providers. The list identifies potential consultants to the transition team and what they offer to the team)

27... Let Your Fingers Do the Walking in Transition Planning (A guide to highlight which phone books would have helpful listings for adolescent transition)

28... Massachusetts State Resources (A list of state agencies/organizations, disability-specific organizations, technology-related assistance, and parent organizations)

33... Work Incentives Transition Network/Understanding the SSI Work Incentives (A fact sheet that provides details on SSI work incentives)

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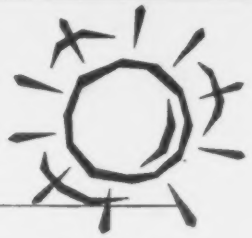
TRANSITION
HEALTH CARE



Family Sheet

Parents of children with special health care needs and disabilities need to plan, connect, advocate and find information on behalf of their child. Planning ahead is very important and makes a difference.

This fact sheet on health care transition explains important issues and lists practical steps that should be addressed in adolescence. The fact sheet discusses two aspects of health care transition. The first aspect is the need for increased responsibility by the adolescent for his/her own health care. The second is the need for families to plan for transfer of care from the pediatric provider to the adult provider.

Read the sheet and refer to it every now and then as you travel through the transition process with your adolescent.

- Begin by age 14 but plan over a period of time. Make a plan that is specific to your adolescent and his/her special health care needs.
- If your adolescent has a special health care need or disability significant enough to interfere with his/her ability to make financial and medical decisions, you will need to file a petition to the court six months before your adolescent turns 18 to maintain guardianship or to initiate conservatorship.
- Ask the provider how and when age-appropriate information will be shared with your adolescent about: his/her disability or chronic illness, sexuality, preparing for parenthood, genetic counseling, vocational awareness, work opportunities and leisure time.
- Suggest to the provider that he/she meet privately with your adolescent to discuss topics such as physical, emotional and sexual development, relationships and friendships, sexuality, alcohol, drug and tobacco use, and family issues.
- Ask the provider who on his/her staff can assist you in care coordination.
- Ask the primary care provider or nurse for help in identifying others such as school nurses and personal care attendants who can help manage your adolescent's care.
- Talk to your adolescent about his/her condition and/or disability in a way that he/she can understand. If your adolescent has developmental disabilities, work with his/her primary care provider to choose the key points and figure out how to make them clear.
- Help your adolescent understand the importance of the medication he/she takes.

- Encourage your adolescent to make his/her own health care appointments.
- Encourage your adolescent to prepare for doctor visits by writing down questions in advance. He/she should also keep his/her own health notes and records.
- Begin teaching your adolescent about his/her insurance coverage.
- Discuss with the primary care provider when you should consider transferring your adolescent's care to an adult provider.
- If you decide that you should work towards a transfer of care, work with your adolescent's primary care provider to find appropriate adult providers.
- Talk to other families and young adults with similar special health care needs and disabilities to help you identify an appropriate adult health care provider for your adolescent.
- Schedule an interview visit with possible adult providers before transferring your adolescent's care. If possible, encourage your adolescent to call and schedule the visit.
- Visit with each provider to determine if he/she is a good match for your adolescent.
- Ask your primary provider to transfer your adolescent's medical records prior to transfer of health care to the adult provider.

For more information...

Family TIES

Family TIES (Together In Enhancing Support) of Massachusetts is a statewide information and parent-to-parent support project for families of children with special needs and chronic illness.

Massachusetts Department of Public Health
Southeast Regional Office
109 Rhode Island Road
Lakeville, MA 02347
800-905-TIES (in-state)
www.massfamilyties.org

Exceptional Parent 2000 Annual Resource Guide

A resource guide providing information, support, ideas, encouragement and outreach for parents and families of children with disabilities and the professionals who work with them.

555 Kinderkamack Road
Oradell, NJ 07649-1517
201-634-6550
www.eparent.com

Produced by the Institute for Community Inclusion at Children's Hospital, Boston, as part of the Massachusetts Initiative for Youth with Disabilities, a project of the Massachusetts Department of Public Health. Supported in part by project #H01MC00006 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

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Transition ~ Health Care

Taking Charge of Your Health Care:

A handout for adolescents and young adults with special health care needs and disabilities

Be your own health care advocate

- Learn about your condition or disability.
- Know the warning signs that mean you need emergency help.
- Know who to call in case of an emergency. Carry that information with you.
- Learn how to make your own appointments.
- Write down any questions you have before you go the doctor's office.
- Meet privately with your doctor/nurses and others.
- Speak up and ask your doctor or nurse questions. If you don't understand an answer, ask again.
- Talk to your doctor about difficult topics such as relationships, drugs, and birth control.
- Tell your doctor if you are feeling down. Your doctor can suggest people to talk to.
- Ask your doctor to explain all tests and their results.
- Ask for copies of medical tests or reports.
- Carry your insurance card and other health care information that you think is important.

Take charge of your health care information

- Be sure to understand the medications that you are taking. What are their names and when do you take them?
- Know how to call your pharmacy and how to fill your prescriptions.
- Make sure you know your insurance and how to get a referral.
- Keep a list of addresses and telephone numbers of all your doctors and nurses.
- Keep a notebook of your doctor reports, medications, operations and results of medical tests.
- Ask your doctor for a short written summary of your health condition.
- Know how to order and take care of any special equipment you use.

Plan for transfer to an adult doctor

- Talk to your doctor about how and when you should start seeing an adult doctor.
- Discuss with your doctor resources that might be helpful to you.
- Meet and talk with the new adult care doctor before you switch.

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For more information...

Family TIES

Family TIES (Together In Enhancing Support) of Massachusetts is a statewide information and parent-to-parent support project for families of children with special needs and chronic illness.
Massachusetts Department of Public Health
Southeast Regional Office
109 Rhode Island Road
Lakeville, MA 02347
800-905-TIES (in-state)
www.massfamilyties.org

Band-Aides and Blackboards-Growing Up with Chronic Illness

This web site is about growing up with a medical problem. Its goal is to help people understand what it's like, from the perspective of the children and teens who are doing just that.
Joan Fleitas, Ed.D., R.N.
Associate Professor of Nursing, Fairfield University
Fairfield, CT 06430
http://funrsc.fairfield.edu/~jfleitas/contents.html

Children with Disabilities

This website offers information for families, service providers, and other interested individuals on topics such as advocacy, education, housing, health and recreation. There is a "Youth to Youth" page.
www.childrenwithdisabilities.ncjrs.org

Keep yourself healthy, exercise, and eat a good diet...

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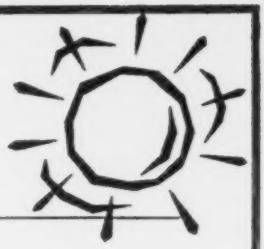
TRANSITION
EDUCATION



Family Sheet

Parents devote enormous amounts of energy, time and emotion to finding the right school programs, working with schools and helping their children learn.

Your adolescent should play an increasing role in the educational planning process, attending team and IEP meetings, becoming involved in transition planning, and being his/her own advocate. This shift of responsibility from family to teen, called for in federal law, reinforces your adolescent's growing independence.

Families need to start the educational transition planning process by the time their adolescent is 14 as reflected by requirements of federal law. This does not mean that final decisions need to be made by this age. But by starting to pay attention to the issues, being aware of the choices and taking one step at a time, families can build for their adolescent's future.

Read these tips now, and then reread them later to remind you of what it takes to create a smooth and effective educational transition plan.

- Begin early so you will have more time to plan, explore, and experience options.
- Initiate discussions with your adolescent about dreams for the future. Let his/her vision drive planning.
- Plan over a period of time but initiate discussion about educational goals and plans within your family at around age 13.
- Remember that your adolescent has a legal right to participate in school team meetings starting at age 14. You may choose to include your child at an earlier age.
- Beginning at age 14 the student's school team must address and include transition planning in the IEP. Planning should focus on the student's course of study and instruction (such as participation in advanced placement courses or a vocational education program).
- Beginning at age 16 a statement of needed transition services must be included in the student's IEP. It should focus on the goals, objectives, activities, and services related to transition. Needed linkages among agencies should be identified.
- Remember that transition services must be based on your adolescent's preferences and interests.
- Transition services should address: instruction, related services, community experiences, post high school plans and any functional vocational evaluation and daily living skills needed, if appropriate.
- At age 18, a student becomes responsible for making all decisions about medical and educational programs and services. Parents no longer have decision-making authority unless guardianship or conservatorship has been legally established or other arrangements have been made with the team and documented.
- For students who will continue to need services as adults, the law requires that a two-year planning process must begin prior to graduation or turning 22. An Individual Transition Plan (ITP) must be developed. This ITP outlines service needs and identifies responsible agencies.

- Be aware of federal and state laws to guide delivery of educational services to children with disabilities and special health care needs. If a child is eligible for special education, these services can begin at any age and continue to age 22.
- Educate yourself about both special education laws and Section 504 of the Rehabilitation Act of 1973.
- Remember that even a student who is not eligible for special education may be eligible for 504 accommodations such as large print books, books on tape or extra time for test taking.
- Put together a student personal file including:
  - Individualized Education Program (IEP)
  - Team meeting notes
  - Evaluations and assessments
  - Records/notes about any services, interventions
  - Notes from any meetings related to special education
  - Copies of any letters concerning services
- Help your child put together a portfolio that presents his/her schoolwork and work done outside of school such as:
  - projects from recreational programs
  - vision statement
  - art work
  - school work sample
  - community activities
  - clubs/organizations
  - awards/commendations
- Be aware that all special education services will end when your adolescent reaches age 22 or when he/she graduates with a diploma or withdraws from high school.
- Remember that an important part of transition planning includes identifying appropriate educational, vocational, and independent living options.
- Ask your adolescent's health care providers (doctors and school nurses) to participate in the educational planning process by sharing information and resources.
- Network with other families who have already been through the educational transition process.
- Develop a list of disability organizations and written resources on education that may be helpful.
- Request school team meetings that will specifically focus on transition planning issues. The first part of any team meeting should focus on transition.
- Learn about the role of the educational consultant or advocate. Ask the Dept. of Education for information.

For more information...

Massachusetts Department of Education

The state agency responsible for education oversight in Massachusetts.
350 Main Street
Malden, MA 02448
781-388-3300
www.doe.mass.edu

Federation for Children with Special Needs

Provides information, support and assistance to parents of children with disabilities, their professional partners, and their communities.
1135 Tremont Street, Suite 420
Boston, MA 02120
617-236-7210 | 800-331-0688 (in MA)
www.fcsn.org

HEATH Resource Center

National clearinghouse on post-secondary education for individuals with disabilities.
One Dupont Circle NW, Suite 800
Washington, DC 20036-1193
202-939-9320
www.acenet.edu

Institute for Community Inclusion

The ICI provides training, clinical service and research in the areas of employment, education, transition, recreation for individuals with special health care needs and disabilities. (See Massachusetts Partnership for Transition "message board on transition" on their web site).
Children's Hospital
300 Longwood Avenue
Boston, MA 02115
617- 355-6506
617- 355-6956 (TTY)
www.childrenshospital.org/ici

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Transition ~ Education

Taking Charge of Your Education:

A handout for adolescents and young adults with special health care needs and disabilities

Get to know your rights

- Learn about your rights. You are your best advocate. Call the Federation for Children with Special Needs for information.
- You are in the driver's seat. Make sure your transition planning is driven by you!!
- Attend school team meetings. Consider asking to start the meetings by telling people about your goals, dreams and by sharing examples of your work.
- At age 14 the law says that you have a right to participate in school team meetings. You may even attend at a younger age, with the permission of your family and school staff.
- Ask about accommodations. You may be entitled to accommodations in school because of your special health care need or disability, even if you are not eligible for special education.
- Be aware that if you leave high school or graduate before you are 22, you will stop receiving special education services. Special education services end for everyone at age 22.
- Know that when you reach age 18, you have the right to approve your own Individualized Education Program (IEP). You and your family may decide to share decision-making or to have your family continue to approve the plan until you reach age 22.
- Start talking to agencies that might help you as you get older.

Start thinking about whether you want or need more schooling after high school

- Think about the kind of job you would like to have as an adult. The earlier you begin to think about this, the more steps you can take to reach your goals.
- Talk with your family, your guidance counselor, and other adults you trust about your dreams, and the kind of preparation that you need. What types of classes should you take in high school? Will you need more schooling after high school?
- Even if you don't want a degree, you can learn a lot by attending classes at a community college.
- Find out about different educational programs after high school: vocational programs; colleges; technical training programs; and adult and continuing education programs. Learn what it takes to get into one of these programs or schools.
- Arrange to visit different schools to make sure they meet your needs and physical challenges.

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Put paperwork together that will help you reach your goals

- Keep your own notes and records from school team meetings that you attend.
- Save examples of your schoolwork and other items that show the kind of work you have been doing, your interests and strengths. Include examples of your life in your community, clubs/organizations.
- Make a list of disability organizations and other places that can help you in planning and paying for any future education.

For more information...

Massachusetts Department of Education

The state agency responsible for oversight of education in Massachusetts.
350 Main Street
Malden, MA 02448
781-388-3300
www.doe.mass.edu

Federation for Children with Special Needs with Special Needs

Provides information, support and assistance to parents of children with disabilities, their professional partners, and their communities.
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Boston, MA 02120
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Provides training, clinical service and research in key interest areas of employment, education, transition, recreation for individuals with special health care needs and disabilities. (See Massachusetts Partnership for Transition (MPT) "message board on transition" on their web site).
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Joan Fleitas, Ed.D., R.N.
Associate Professor of Nursing
Fairfield University
Fairfield, CT 06430
http://funrsc.fairfield.edu/~jfleitas/sitemap.html

Think positive, plan ahead, talk to people who can help you...

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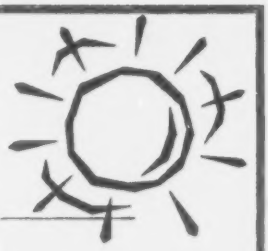
TRANSITION

EMPLOYMENT



Family Sheet

It is possible for adolescents with special health care needs and disabilities to find employment after they leave school, given proper planning and preparation. Different approaches work for different teens. Some adolescents go directly from high school to a job. For some, this transition involves linking the adolescent to supports such as job coaching. Other adolescents go on to further education past high school.

Adolescents need encouragement to become their own advocates in the employment area. Families can help adolescents think about channeling their interests, strengths and talents into a job. Adolescents need to find ways to learn about job possibilities and opportunities. They need to connect with and learn from others who have entered the job market. Families can encourage them to discuss their plans with guidance counselors, teachers and medical providers. All adolescents will benefit from the attention paid to the development of job skills and experiences.

Read these tips now, and then reread them later to remind you of what it takes to create a smooth and effective transition to employment.

- Begin thinking about work early. Children can learn about the world of work as early as preschool by watching family members, and helping out at home.
- Adolescents with special health care needs and disabilities can work.
- Identify early on the supports and services that your adolescent will need in order to be successful in the workplace.
- Discuss personal likes, strengths, abilities and the future goals of your adolescent.
- Encourage your adolescent to be his/her own advocate.
- Incorporate activities in the home, school and community that build on strengths and develop new skills.
- Involve your adolescent in the transition planning process by having him/her attend school meetings and review the IEP. Legally, he/she has the right to attend starting at age 14.
- Beginning at age 14 and updated yearly, a statement of the transition service needs must be included in the IEP. At this early stage, the statement focuses on the student's courses of study and instruction (such as participation in advanced placement courses or a vocational education program).
- Beginning at age 16 (or younger if determined appropriate by the IEP team), a statement of needed transition services must be included in the student's IEP. This statement focuses on the goals, objectives, activities, and services related to transition. It also identifies any needed linkages among agencies.

- Remember that transition services must be based on your adolescent's preferences and interests. Make sure transition services address: instruction, related services, community experiences, post high school plans and any functional vocational evaluation and daily living skills needed, if appropriate.
- Contact family advocacy and employment support organizations to learn about community and state agencies .
- Understand that employment services can range from resume preparation, job placement assistance, and employment counseling, to job coaching, travel training, and benefits management.
- Discuss supported employment options with your adolescent. Supported employment offers work experiences for people with disabilities by placing them in settings with training and support.
- Consider having your adolescent participate in a vocational assessment as a way to focus in on work-related interests, abilities and strengths.
- Contact the Social Security Administration or the Department of Public Health about programs that may offer financial assistance.
- Learn about the state regulations regarding employment for people with disabilities.
- Notify appropriate adult service agencies when planning for transition. Vocational rehabilitation and developmental disabilities organizations should be involved in transition planning.
- Ask your school about local work training programs that can help provide support, job coaching and training to the adolescent.
- Understand that employment training is an important part of the Individualized Education Program.
- Make job placement an integral part of your adolescent's education plan.
- Remember that work experience can be helpful for all transition-age youth, including students planning to go to college.
- Encourage self-care such as personal grooming, hygiene, money management, and physical fitness.
- Encourage your adolescent to participate in volunteer activities in order to learn about possible job opportunities and to develop job skills.
- Discuss with your adolescent and service provider the types of job accommodations your adolescent will need in the workplace.
- Contact the local Social Security Office to learn about the impact of earnings on your son or daughter's benefits and to learn about Social Security Work Incentives.

For more information...

Institute for Community Inclusion

Provides training, clinical service and research in key interest areas of employment, education, transition, recreation for individuals with special health care needs and disabilities. (See Massachusetts Partnership for Transition (MPT) "message board on transition" on their web site).
Children's Hospital
300 Longwood Avenue
Boston, MA 02115
617- 355-6506
617- 355-6956 (TTY)
www.childrenshospital.org/ici

Massachusetts Rehabilitation Commission

"Mass Rehab" is the state agency that assists individuals with disabilities to live independently and go to work. The agency is responsible for Vocational Rehabilitation Services and Independent Living Services, among others.
27-43 Wormwood Street
Boston, MA 02210-1616
617- 204-3600
www.state.ma.us/mrc

Social Security Administration

10 Causeway Street
Boston, MA
800-772-1213
www.ssa.gov

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Transition to Employment

Taking Charge of Getting a Job:

A handout for adolescents and young adults with special health care needs and disabilities

You CAN work!

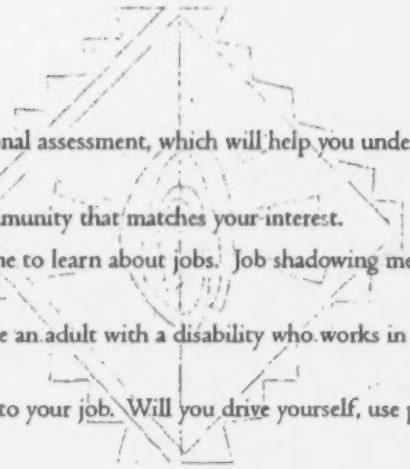
- Think about your future. What do you want to be when you grow up?
- Identify what you are good at doing and what you like to do.
- Learn about the responsibilities involved in having a job.
- Think about how your special health care need or disability might affect the kind of job you can do.
- Will you need accommodations? Accommodations are supports or assistance to make it possible for you to work.

Be your own advocate...Speak up for yourself!

- Be a part of the transition planning process at school.
- Attend all of the team meetings related to planning for your future and your Individualized Education Program (IEP). Start the meeting by telling people about your dreams and goals; share examples of your work. Help them get to know you.
- Ask a friend, parent or relative to come to planning meetings with you to help take notes, listen to what is said, or contribute ideas.
- Make sure your teachers and guidance counselors know what your interests are.
- Ask questions and speak up! Let people know what you want to do and what you need.

Preparing for a job

- Look for job opportunities. It's important to start thinking about work early.
- Ask your parents, guidance counselors, doctor or nurse about agencies that might help you plan for a job.
- Consider getting an after school or a weekend job to earn money and get experience.
- Talk to your doctor about how your disability may influence the type of job you choose.
- Learn about supported employment. Supported employment means work in a community setting with ongoing support by an agency that knows how to help people with disabilities find jobs.



- Find out about having a vocational assessment, which will help you understand your work preferences, strengths and abilities.
- Try a volunteer job in your community that matches your interest.
- Think about shadowing someone to learn about jobs. Job shadowing means observing someone "on the job."
- Look for an opportunity to have an adult with a disability who works in the area you are interested in as a mentor.
- Make a plan for transportation to your job. Will you drive yourself, use public transportation or a taxi service?

Make sure you look your best and dress appropriately for the work setting

For more information...

Institute for Community Inclusion

Provides training, clinical service and research in key interest areas of employment, education, transition, recreation for individuals with special health care needs and disabilities.
Children's Hospital
300 Longwood Avenue
Boston, MA 02115
617- 355-6506
617- 355-6956 (TTY)
www.childrenshospital.org/ici

Social Security Administration

10 Causeway Street
Boston, MA
800-772-1213
www.ssa.gov

Massachusetts Rehabilitation Commission

"Mass Rehab" is the state vocational rehabilitation agency which assists individuals with disabilities to live independently and go to work.
27-43 Wormwood Street
Boston, MA 02210-1616
617- 204-3600
www.state.ma.us/mrc

Band-Aides and Blackboards-Growing Up with Chronic Illness

This web site is about growing up with a medical problem. Its goal is to help people understand what it's like, from the perspective of the children and teens who are doing just that.
Joan Fleitas, Ed.D., R.N.
Associate Professor of Nursing
Fairfield University
Fairfield, CT 06430
http://funrsc.fairfield.edu/~jfleitas/sitemap.html

Produced by the Institute for Community Inclusion at Children's Hospital, Boston, as part of the Massachusetts Initiative for Youth with Disabilities, a project of the Massachusetts Department of Public Health. Supported in part by project #HO1MC00006 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

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TRANSITION

RECREATION

Family Sheet

Recreation is more than planned programs that happen in a park or gym. Recreation is any activity that helps a person to explore or relax or have fun. Recreation can happen in the home, on the playground or in a community setting.

For the adolescent with special health care needs, recreation is especially important. The benefits of relaxation, of social connections, and of using minds and bodies in different ways are enormous. Families need to help their adolescent find recreational opportunities. Inviting friends into the home is one way. Shared experiences of listening to a CD or watching a video are every bit as valuable as some structured activities. It helps to know where adolescents gather outside school: the sporting events they attend, the pizza shops they go to; these are all places where they could make friends. Also, it can be important for adolescents with special health care needs and disabilities to spend time with others who have special needs.

Read these tips now, and then reread them later to remind you of what it takes to create rewarding recreational experiences.

- Highlight your adolescent's strengths and interests, not his/her disability.
- Keep fun in your family. Don't forget about the benefits of recreation.
- Create opportunities for your adolescent in your own home as well as in your community.
- Notice what excites your adolescent.
- Make friendships a priority. Adolescents need other adolescents to talk to and share their life with.
- Include recreation in transition planning. Make this a subject for your team meeting.
- Discuss with your adolescent's primary care provider any health-related limitations your adolescent may need to consider when planning recreational activities.
- Identify your adolescent's need for accommodations.
- Encourage your adolescent to "try out" different activities to see what he/she enjoys.
- Interview organizations such as the local YMCA to see if the recreational activities available are a good fit for your adolescent. Teach them about any adaptations or accommodations your adolescent might need to participate in recreation activities.
- Visit the facility where a recreational activity is going to take place to promote proper planning.

- Work with staff of recreation programs to adapt the program to your child's special needs.
- Ask other parents about their successful recreational experiences. Work with other parents to create new recreational options where they don't exist.
- Check out the school or local library for flyers on adolescent activities in your community.
- Surf the Internet. Many communities have recreational Web sites.
- Look in the calendar section of your local newspaper for events close to home where your adolescent can meet other teens.
- Consider the following as contacts for learning about recreational opportunities:
  1. City/town recreation department
  2. Chamber of Commerce
  3. Cultural council in your town or city
  4. Colleges and universities
  5. Health and fitness clubs
  6. YMCA/YWCA
  7. United Way
  8. Easter Seals
  9. Boy/Girl Scouts
  10. Parks and beaches in your local area
- Join condition-specific organizations where adolescents can meet other adolescents with special health care needs.
- Consider participating in a recreational or fitness activity as a family.

For more information...

Institute for Community Inclusion

The Institute provides training, clinical service and research in key interest areas of employment, education, transition, recreation for individuals with special health care needs and disabilities.
Children's Hospital
300 Longwood Avenue
Boston, MA 02115
617-355-6506; 617-355-6956 (TTY)
www.childrenshospital.org/ici

Family TIES

Family TIES (Together In Enhancing Support) of Massachusetts is a statewide information and parent-to-parent support project for families of children with special needs and chronic illness.
Massachusetts Department of Public Health
Southeast Regional Office
109 Rhode Island Road
Lakeville, MA 02347
www.massfamilyties.org
800-905-TIES (in-state)

National Center on Accessibility

NCA is an organization committed to the full participation in parks, recreation and tourism by people with disabilities.
5020 State Road 67 North
Martinsville, Indiana 46151
(765) 349-9240 (voice/TTY)
www.indiana.edu/~nca

Solutions at Disability

A Web site linking people with disabilities and chronic health conditions to resources, products and services that promote active, healthy independent living.
www.eka.com

Produced by the Institute for Community Inclusion at Children's Hospital, Boston, as part of the Massachusetts Initiative for Youth with Disabilities, a project of the Massachusetts Department of Public Health. Supported in part by project #HO1MC00006 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

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Transition ~ Recreation

Taking Charge of Having Fun:

A handout for adolescents and young adults with special health care needs and disabilities

Meet people...make friends

- Work at making friends; it isn't easy for anyone. Reaching out is hard, but it's worth the effort.
- Join clubs or committees that you are interested in. This is a good way to meet people.
- Get to know what other kids are interested in: movies, music, clothes.
- Figure out the people at school who can help you connect with other teens such as a teacher or guidance counselor.
- Go to school functions such as school dances, plays or sports events.
- Spend time with friends with disabilities and special health care needs.
- Spend time with friends who do not have disabilities and special health care needs.

Enjoy recreation in your community

- Try out different activities to find out what you might enjoy.
- Call organizations such as the local YMCA to see if their activities are a good fit for you.
- Visit the place where the activity may be held so that you can plan accordingly.
- Identify your need for accommodations.
- Work with the recreation staff to adapt the program for you.
- Discuss with your doctor any health-related issues you should consider when planning your activities.

Have fun at home

- Keep fun in your family. Take time to enjoy yourself with your family.
- Think about activities you'd like to do at home with a friend.
- Invite friends to your home.
- Ask your parents to let you bring a friend along when you go to places such as the movies.
- Include your friends in activities that you do at home.
- Consider participating in recreation or fitness activities with your family.

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Know where to get information about recreational experiences

- Check out the school or local library for flyers on upcoming activities.
- Ask other adolescents about activities they enjoy and participate in.
- Surf the Internet. Many cities and towns have recreational Web sites.
- Look in the calendar section of the newspaper for events close to home.
- Join a group where you can meet other adolescents with special health care needs and disabilities.
- Consider the following as good places to find out about activities:

1. City/town recreation department
2. Chamber of Commerce
3. Cultural council in your city/town
4. Colleges and universities
5. Health and fitness clubs
6. YMCA/YWCA
7. United Way
8. Easter Seals
9. Boy/Girl Scouts
10. Parks and beaches in your local area

Recreation allows you to meet new people, learn new things and stay fit...Don't forget to have fun!

For more information...

Institute for Community Inclusion

Provides training, clinical service and research in key interest areas of employment, education, transition, recreation for individuals with special health care needs and disabilities.
Children's Hospital
300 Longwood Avenue
Boston, MA 02115
617-355-6506; 617-355-6956 (TTY)
www.childrenshospital.org/ici

Family TIES

Family TIES (Together In Enhancing Support) of Massachusetts is a statewide information and parent-to-parent support project for families of children with special needs and chronic illness.
Massachusetts Department of Public Health
Southeast Regional Office
109 Rhode Island Road
Lakeville, MA 02347
800-905-TIES (in-state)
www.massfamilyties.org

National Center on Accessibility

NCA is an organization committed to the full participation in parks, recreation and tourism by people with disabilities.
5020 State Road 67 North
Martinsville, Indiana 46151
(765) 349-9240 (voice/tty)
www.indiana.edu/~nca

Band-Aides and Blackboards-Growing Up with Chronic Illness

A web site about growing up with medical problems. Its goal is to help people understand what it's like from the perspective of the children and teens who are doing just that.
Joan Fleitas, Ed.D., R.N.
Associate Professor of Nursing
Fairfield University
Fairfield, CT 06430
http://funrsc.fairfield.edu/~jfleitas/contents.html

Solutions at Disability

A Web site linking people with disabilities and chronic health conditions to resources, products and services that promote active, healthy independent living.
www.eka.com

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Resources on the Web:

Adolescent Health Transition Project Center on Human Development and Disability (CHDD) University of Washington
www.depts.washington.edu/healthtr

Band-Aides and Blackboards-Growing Up with Chronic Illness
http://funrsc.fairfield.edu/~jfleitas/sitemap.html

Center for Community Inclusion, Maine University Affiliated Program
Maine Adolescent Transition Partnership
www.ume.maine.edu/cci/matp

Children with Disabilities
www.childrenwithdisabilities.ncjrs.org

Children's Healthcare Options Improved Through Collaborative Efforts and Services (CHOICES)
www.shrinershq.org/Hospitals/choices.html

Children's Hospital Family Education Program - Family Education
www.childrenshospital.org

Department of Transitional Assistance
www.state.ma.us/dta/

Disability Resources Monthly
www.disabilityresources.org

Executive Office of Health and Human Services
www.state.ma.us/eohhs/

Exceptional Parent Magazine
www.eparent.com

Family TIES
www.massfamilyties.org

Federation for Children with Special Needs
www.fcsn.org

HEATH Resource Center
www.acenet.edu

Institute for Child Health Policy
www.ichp.edu/

Massachusetts Department of Education
www.doe.mass.edu

Massachusetts Partnership for Transition: Preparing all youth for adult life (web-based discussion forum)
www.childrenshospital.org/ici/forum

Massachusetts Rehabilitation Commission
www.state.ma.us/mrc

National Center on Accessibility
www.indiana.edu/~nca

National Information Center for Children and Youth with Disabilities (NICHCY)
www.nichcy.org/

National Transition Network
http://ici2.coled.umn.edu/ntn/

Parent Advocacy Coalition for Educational Rights (PACER Center)
www.pacer.org

Social Security Administration
www.ssa.gov

Solutions at Disability
www.eka.com

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Communicating with Doctors and Other Health Care Providers

Talking to doctors and other health care providers can be difficult, overwhelming and, at times, scary. What advice would you give someone going to the doctor? Here are some tips to help you communicate with health care providers. These tips were suggested by adolescents in the "Making Healthy Connections" program.

- Make sure to **ask for a long enough appointment**. Sometimes appointments are very rushed. If you know that you will have a lot to talk about with your doctor, ask for an extended appointment so you don't run out of time.
- **Tell your doctor everything you can about yourself, what you do, and how you feel**. The more information the doctor has, the more helpful he/she can be.
- Bring a **list of questions and concerns**. It's easy to forget things when you're sitting there, in the doctor's office. A written list of questions, concerns, or other things you want to make sure to tell the doctor will help you remember everything that's been on your mind.
- **Say what you think**—and be honest.
- Tell the doctor to be honest and to tell you everything. **You're entitled to know all** about your condition, your treatment, and any options that might be available to you.
- **Be assertive**. Be nice, but persistent.
- **Ask questions**. Remember—there's no such thing as a stupid question. If you don't understand an answer to a question, ask the doctor to explain it again until you do understand it.
- **Write down what the doctor says.** That will help you remember later on.
- **Bring someone with you**, if you'd like. Sometimes it helps to have someone else there for support, to hear what the doctor has to say, or to ask questions that you might not think of.
- Ask your parents to wait outside the exam room so you **have some time alone to talk to the doctor, if you'd like.** Sometimes that helps the doctor focus on you and what you have to say. Your parents can come back in after you've had a chance to talk to the doctor yourself. Then they can ask their questions.
- **If you need help, ask for it.**
- When visiting a new doctor, **ask the doctor about his/her background and experience**.
- Even if you've seen your doctor for a long time, **it's ok to ask about the doctor's background** and what his/her experience has been.
- Call back if you have any questions after the appointment. Sometimes questions come up after you get home, or you forget something the doctor said. **It's ok to call and follow up with more questions.**
- **Learn about your insurance coverage.** What services are covered and what procedures do you have to follow to get those services?

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Health Care Skills Checklist

Note: This health care checklist can be used to set goals for achieving independence in managing one's own health.

Skill	Performs Independently	Performs Partially	Needs Practice	Plan to start	Skill Accomplished	Comments
Describes chronic illness or disability	❑	❑	❑	❑	❑	
Understands implications of chronic illness/disability on daily life	❑	❑	❑	❑	❑	
Accesses medical records, diagnosis information, etc.	❑	❑	❑	❑	❑	
Prepares and asks questions for doctors, nurses, therapists	❑	❑	❑	❑	❑	
Knows medications and what they're for, or carries information in wallet	❑	❑	❑	❑	❑	
Is responsible for taking own medication	❑	❑	❑	❑	❑	
Is responsible for doing own treatments	❑	❑	❑	❑	❑	
Gets a prescription filled/refilled	❑	❑	❑	❑	❑	
Calls to schedule own medical/dental appointments	❑	❑	❑	❑	❑	
Keeps a calendar of medical appointments	❑	❑	❑	❑	❑	
Knows transportation to medical office	❑	❑	❑	❑	❑	
Knows height/weight, birthdate, or carries information in wallet	❑	❑	❑	❑	❑	
Knows how to use and read thermometer	❑	❑	❑	❑	❑	
Knows health emergency phone numbers, or carries info in wallet	❑	❑	❑	❑	❑	
Knows medical coverage numbers, or carries information in wallet	❑	❑	❑	❑	❑	
Knows about medical insurance coverage	❑	❑	❑	❑	❑	

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Skill	Performs Independently	Performs Partially	Needs Practice	Plan to start	Skill Accomplished	Comments
Obtains sex education materials/birth control/family planning information as needed	❑	❑	❑	❑	❑	
Discusses role of general health maintenance	❑	❑	❑	❑	❑	
Has considered genetic counseling if appropriate	❑	❑	❑	❑	❑	
Knows about how drugs/alcohol affect illness/disability	❑	❑	❑	❑	❑	
Makes contact with appropriate community advocacy organizations	❑	❑	❑	❑	❑	
Takes care of own menstrual needs and keeps a record of monthly periods	❑	❑	❑	❑	❑	
Has considered the need for a health advocate	❑	❑	❑	❑	❑	
Has identified a physician for adult care	❑	❑	❑	❑	❑	
Knows how to hire and manage a personal care attendant	❑	❑	❑	❑	❑	
	❑	❑	❑	❑	❑	
	❑	❑	❑	❑	❑	
	❑	❑	❑	❑	❑	
	❑	❑	❑	❑	❑	
	❑	❑	❑	❑	❑	
	❑	❑	❑	❑	❑	

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Planning for Education after High School

What Does This Student Need?	Actions the High School Transition Team May Recommend
ASSESSMENT that identifies strengths, needs, interests, preferences for post secondary education	✓ Assess student's self-advocacy skills, academic preparation, and college bound test scores ✓ Assess student's technical skills, social skills, independent living skills. ✓ Interview youth regarding educational setting interests and preferences: size, setting, programs. (Use other methods to assess interests and preferences if student is nonverbal) ✓ Identify youth's long-term career goals ✓ Develop a list of supports student needs to achieve post secondary education goals ✓ Discuss health care issues that may impact student in post secondary setting ✓ Identify needed natural supports, academic or physical accommodations, and support services
DEVELOPMENT of post secondary education options	✓ Visit campuses ✓ Participate in college night ✓ Have college students with disabilities talk to youth ✓ Research colleges and universities that offer special services to students with disabilities ✓ Discuss financial issues ✓ Discuss preferred location of college
MATCHING of student and post secondary education setting	✓ Analyze the demands and expectations of the post secondary education setting—accessibility, support services availability, academic rigor, social culture, independent living setting ✓ Match the student's assessment and list of needed supports to the demands of the post secondary education setting
PREPARATION for post secondary education	✓ Provide developmental academic support and coursework needed to prepare for post secondary education goals ✓ Assist youth with applications, interviews, and test preparation ✓ Identify potential service providers ✓ Develop natural supports ✓ Provide self-advocacy training
PLACEMENT and FOLLOW-UP	✓ Monitor progress in the post secondary setting ✓ Monitor changing need for natural supports ✓ Monitor changing need for services ✓ Advocate for changes and adjustments, as needed

Source: National Information Center for Children and Youth with Disabilities, PO Box 1492, Washington, DC 20013 (800) 695-0285 (voice/TTY); www.nichcy.org

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Potential Consultants to the Transition Team

Potential Consultant	Relationship to Transition Services
Adult Education Representative	Provides information about lifelong education options
Advocacy Organization(s) Representative	May offer self-advocacy training or support groups for young adults
Assistive Technology Representative	Provides expertise on devices that can open doors to opportunities
At-Risk/Prevention Specialist	Offers counseling and support on teen pregnancy, alcohol, and drugs
Business-Education Partnership Representative	Provides links between schools and local businesses and industry
Community Action Agency Representative	May link team to resources for traditionally underrepresented groups
Correctional Education Staff	Provides incarcerated youth with continued learning opportunities
Drop-Out Prevention Representative	Provides youth with alternatives to dropping out of school
Employer	Offers insight into expectations; promotes hiring of people with disabilities
Employment Specialist	Provides job development, placement, coaching
Extension Service Agent	Offers programs in parenting, homemaking, independent living
Guidance Counselor	Provides info on curriculum, assessment, graduation requirements, college
Health Department/ School Nurse	Provides guidance on community health services and health care advice
Higher Education Representative	Provides information on post secondary services to students with disabilities
Housing Agency Representative	Assists in developing housing options
Leisure Program Representative	Knows available program options within the community
Literacy Council Representative	Coordinates volunteers to teach basic reading and writing skills
Local Government Representative	Funds many local services; can provide information on local services
Local Disability Representative (e.g., UCP)	Provides information and training (often serves all disabilities, not just one)
Parent Training Information Center Rep.	Provides training on transition planning and advocacy services to families
Religious Community Member	Can provide social support to young adults and their families
Residential Service Provider	Can help access specialized housing
Social Worker	Provides guidance and arranges for case management, support, respite care
Special Olympics Representative	Provides sports training, competition, and recreational opportunities for youth
Therapists	Provide behavioral, physical, occupational, & speech services in the community
Transportation Representative	Offers expertise about transportation options and training
United Way Representative	Funds many community programs that may offer options for young adults
Very Special Arts Representative	Provides information on art programs and opportunities for youth
Vocational Educator	Provides job training; teaches work-related skills
YMCA/YWCA	Offers recreation and leisure programs

Source: National Information Center for Children and Youth with Disabilities, PO Box 1492, Washington, DC 20013 (800) 695-0285 (voice/TTY); www.nichcy.org

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Let Your Fingers Do the Walking in Transition Planning

White Pages

The Table of Contents may include references such as "Community Service Numbers" or "Disabilities, Services for Individuals with."

Some of the headings you will find that might relate to the varying service needs of youth with disabilities include:

- Adult Protection
- Disabilities Services
- Education
- Employment
- Financial Aid
- Handicapped/Disabled
- Housing
- Human Rights
- Human Services
- Mental Health & Mental Retardation
- Recreational/Social Development
- Rehabilitation
- Social Security Administration
- Social Services
- Transportation
- Volunteer Opportunities

Blue Pages

Local, state, and federal government listings can always be found in the Blue Pages of the phone book.

Local Listings might have some of the following headings:

- Employment Opportunities & Information
- Housing
- Human Resource Management
- Mayor's Office on Disability
- Social Security

State Listings might have some other headings:

- Children
- Clinics
- Education
- Health Services
- Housing
- Labor
- Libraries
- Museums & Theaters
- Social Services

Local, State and Federal Government Listings will include numbers for all state and government agencies. Examples of these would be:

- Employment Commission
- Medicaid
- Mental Health
- Mental Retardation
- Rehabilitation Services
- Social Services
- Transitional Living Center
- Transportation Department
- Vocational Evaluation Center

Yellow Pages

Check out the *Index of commonly used terms.* Using key words, here are examples of what you might find:

Disability:
Access Unlimited; Adult Care Services; Assisted Living; Charter's Mobility Center; Paradapt Services

Associations:
Arc; Boy Scouts; Families for Children with Mental Health Concerns; Information & Referral-United Way; Learning Disabilities Council; Neighborhood Housing Services

Mental Health:
Alliance for the Mentally Ill

Source: National Information Center for Children and Youth with Disabilities, PO Box 1492, Washington, DC 20013 (800) 695-0285 (voice/TTY); www.nichcy.org

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Massachusetts State Resources

Developed by National Information Center for Children and Youth with Disabilities

UNITED STATES SENATORS

Honorable Edward M. Kennedy (D)
315 Russell Senate Office Building
United States Senate
Washington, DC 20510-2101
(202) 224-4543
(202) 224-2417 (Fax)
E-mail: senator@kennedy.senate.gov
Web: www.senate.gov/~kennedy

Honorable John F. Kerry (D)
United States Senate
Washington, DC 20510-2102
(202) 224-2742
(202) 224-8525 (Fax)
E-mail: john_kerry.senate.gov
Web: www.senate.gov/~kerry

GOVERNOR

Argeo Paul Cellucci, Governor
State House, Room 360
Boston, MA 02133
(617) 727-9173
E-mail: Goffice@state.ma.us
Web: www.state.ma.us/gov/gov.htm

STATE DEPARTMENT OF EDUCATION: SPECIAL EDUCATION

Marcia Mittnacht, Director
Office of Special Services
Department of Education
350 Main Street
Malden, MA 02148-5023
(781) 338-3000; (781) 338-3388
E-mail: mmittnacht@doe.mass.edu
Web: www.doe.mass.edu

STATE VOCATIONAL REHABILITATION AGENCY

Elmer C. Bartels, Commissioner
MA Rehabilitation Commission
Fort Point Place
27-43 Wormwood Street
Boston, MA 02210-1616
(617) 204-3600

OFFICE OF STATE COORDINATOR OF VOCATIONAL EDUCATION FOR STUDENTS WITH DISABILITIES

Francis Kane, Administrator
School to Career
Department of Education
350 Main Street
Malden, MA 02148-5023
(781) 388-3300
E-mail: fkane@doe.mass.edu

STATE MENTAL HEALTH AGENCY

Marylou Sudders, Commissioner
Department of Mental Health
25 Staniford Street
Boston, MA 02114
(617) 727-5600

STATE MENTAL HEALTH REPRESENTATIVE FOR CHILDREN AND YOUTH

Joan Mikula, Assistant Commissioner
Child and Adolescent Services
Department of Mental Health
25 Staniford Street
Boston, MA 02114
(617) 727-5600
E-mail: jmikula@state.ma.us

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STATE MENTAL RETARDATION AGENCY

Gerald J. Morrissey Jr., Commissioner
Department of Mental Retardation
160 North Washington Street
Boston, MA 02114
(617) 727-5608
Web: www.dmr.state.ma.us

STATE DEVELOPMENTAL DISABILITIES PLANNING COUNCIL

Daniel Shannon, Director
MA Developmental Disabilities Council
174 Portland Street, 5th Floor
Boston, MA 02114
(617) 727-6374 ext. 100
(617) 727-1885 (TTY)
E-mail: Daniel.Shannon@state.ma.us

PROTECTION AND ADVOCACY AGENCY

Christine Griffin, Acting Executive Director
Disability Law Center, Inc.
11 Beacon Street, Suite 925
Boston, MA 02108
(617) 723-8455
(800) 872-9992
(617) 227-9464 (TTY)
(800) 381-0577 (TTY)
Web: www.dlc-ma.org/

CLIENT ASSISTANCE PROGRAM

Barbara Lybarger, Director
Client Assistance Program
MA Office on Disability
One Ashburton Place, Room 1305
Boston, MA 02108
(617) 727-7440
(800) 322-2020 (In MA)
E-mail blybarger@state.ma.us

PROGRAMS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Deborah Allen, Director
Division for Special Health Needs
Department of Public Health
250 Washington Street, 4th Floor
Boston, MA 02108-4619
(617) 624-5070
E-mail: deborah.allen@state.ma.us
Web: www.magnet.state.ma.us/dph

STATE AGENCY FOR THE VISUALLY IMPAIRED

David Govostes, Commissioner
MA Commission for the Blind
88 Kingston Street
Boston, MA 02111
(617) 727-5550
(800) 392-6450
(800) 392-6556 (TTY)
E-mail: David.Govostes-MCB@state.ma.us

PROGRAMS FOR CHILDREN AND YOUTH WHO ARE DEAF OR HARD OF HEARING

Barbara Jean Wood, Commissioner
MA Commission for the Deaf and Hard of Hearing
210 South Street, 5th Floor
Boston, MA 02111
(617) 695-7500; (617) 695-7600 (TTY)
(800) 882-1155 (V, in MA only)
(800) 530-7570 (TTY, in MA only)
(800) 249-9949 (V/TTY in MA- after hours emergency)
E-mail: BJ.Wood@state.ma.us

REGIONAL ADA TECHNICAL ASSISTANCE AGENCY

New England ADA Technical Assistance Center
Adaptive Environments Center, Inc.
374 Congress Street, Suite 301
Boston, MA 02210
(617) 695-0085 (V/TTY)
(800) 949-4232 (V/TTY)
E-mail: adaptive@adaptenv.org
Web: www.adaptenv.org

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DISABILITY ORGANIZATIONS

Attention Deficit Disorder

To identify an ADD group in your state or locality, contact either:

Children and Adults with Attention-Deficit/ Hyperactivity Disorder (CH.A.D.D)
8181 Professional Place, Suite 201
Landover, MD 20785
(301) 306-7070
(800) 233-4050 (Voice mail to request information packet)
E-mail: national@chadd.org
Web: www.chadd.org

National Attention Deficit Disorder Association (ADDA)
P.O. Box 1303
Northbrook, IL 60065-1303
E-mail: mail@add.org
Web: www.add.org

Autism

To identify an autism group in your state, contact:
Autism Society of America
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(301) 657-0881; (800) 3-AUTISM
Web: www.autism-society.org

Brain Injury

Massachusetts Brain Injury Association
Denholm Building
484 Main Street, #325
Worcester, MA 01608
(508) 795-0244; (800) 242-0030 (in MA)
E-mail: mbia@mbia.net
Web: www.mbia.net

Cerebral Palsy

Todd Kates, Executive Director
United Cerebral Palsy of MetroBoston, Inc.
71 Arsenal Street
Watertown, MA 02472
(617) 926-5480
E-mail: UCPBOST@aol.com

Epilepsy

Epilepsy Foundation of MA & RI
William Murphy, Executive Director
95 Berkeley Street, Suite 409
Boston, MA 02116
(617) 542-2292
E-mail: efmri@aol.com

Learning Disabilities

Learning Disabilities Association of MA
Teresa Citro, Executive Director
1275 Main Street
Waltham, MA 02451
(781) 891-5009 (T-W-Th, 9-2 pm)
Web: www.ldanatl.org (select MA)

Mental Health

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314-2971
(800) 969-6642; (703) 684-7722

National Alliance of the Mentally Ill in Massachusetts
Toby Fisher, Executive Director
400 W. Cummings Park, Suite 6650
Woburn, MA 01801
(781) 938-4048; (800) 370-9085
E-mail: namimass@aol.com
Web: www.namimass.org

Parent/Professional Advocacy League (PAL)
Donna Welles, Director
14 Beacon Street, Suite 706
Boston, MA 02108
(617) 227-2925
E-mail: pal@fcsn.org

Mental Retardation

ARC Massachusetts
Leo Sarkissian, Executive Director
217 South Street
Waltham, MA 02453
(781) 891-6270
E-mail: arcmass@gis.net
Web: www.gis.net/~arcmass/

Greater Boston ARC
Terri Angerloni, Executive Director
1505 Commonwealth Avenue
Boston, MA 02135
(617) 783-3900
E-mail: BostonArc@aol.com

The ARC of Northern Bristol County
Tammara Beane, Executive Director
5 Bank Street
Attleboro, MA 02703
(508) 226-1445
E-mail: Archbctrb@aol.com

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Speech and Hearing
Robert Gilmore, President
MA Speech-Language-Hearing Association
200 Reservoir Street, Suite 309A
Needham, MA 02494
(781) 444-4098; (800) 898-8177
E-mail: mshahq@aol.com
Web: www.healthcaresource.com/msha

Spina Bifida
MA Spina Bifida Association
456 Lowell Street
Peabody, MA 01960-2741
(978) 531-1034

Visual Impairments
Regina Genwright, Director of Information Center
American Foundation for the Blind
11 Penn Plaza, Suite 300
New York, NY 10001
(212) 502-7600; (212) 502-7662 (TTY)
E-mail: afbinfo@afb.org

UNIVERSITY-AFFILIATED PROGRAMS

Institute for Community Inclusion UAP
William E. Kiernan, Director
Children's Hospital
300 Longwood Avenue
Boston, MA 02115
(617) 355-6506; (617) 355-6956 (TTY)
Web: www.childrenshospital.org/ici

Eunice Shriver Center UAP
200 Trapelo Road
Waltham, MA 02452-6319
(781) 642-0001; (800) 764-0200 (TTY)
Web: www.shriver.org

TECHNOLOGY-RELATED ASSISTANCE

MA Assistive Technology Partnership
Marylyn Howe, Project Director
MATP Center; Children's Hospital
1295 Boylston Street, Suite 310
Boston, MA 02215
(800) 848-8867 (V/TTY, in MA only);
(617) 355-7820
(617) 355-7301 (TTY)
E-mail: howe_m@al.tch.harvard.edu
Web: www.matp.org

PARENT TRAINING AND INFORMATION PROJECT

Federation for Children with Special Needs
Richard Robison, Executive Director
1135 Tremont Street, Suite 420
Boston, MA 02120-2140
(617) 236-7210 (V/TTY);
(800) 331-0688 (in MA only)
E-mail: fcsninfo@fcsn.org
Web: www.fcsn.org/

PARENT-TO-PARENT

Family TIES
Polly Sherman, Network Director
c/o MA Dept. of Public Health
Southeast Regional Office
109 Rhode Island Road
Lakeville, Massachusetts 02347
(508) 947-1231; (617) 727-1440
polly.sherman@state.ma.us

Massachusetts Families Organizing for Change
P.O. Box 61
Raynham, MA 02768
(800) 406-3632
E-mail: mfofc@tmlp.com
Web: www.communitygateway.org/mfofc

PARENT TEACHER ASSOCIATION (PTA)

Massachusetts Parent-Teacher-Student Association
Joyce Knippenberg, President
P.O. Box 710
Fiskdale, MA 01518-0710
(888) 404-4782
E-mail: masspta@aol.com
Web: www.masspta.org

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OTHER DISABILITY ORGANIZATIONS

Easter Seals Massachusetts
(call for info about assistive technology, recreation, and therapy)
Kirk Joslin, President
484 Main Street
Worcester, MA 01608
(508) 757-2756
Web: www.eastersealsma.org

Statewide Head Injury Program
Massachusetts Rehabilitation Commission
Debra S. Kamen, Director
27-43 Wormwood Street
Boston, MA 02210
(617) 204-3852 (V); (617) 204-3817 (TTY)
E-mail: shipu@state.ma.us
Web: www.state.ma.us/mrc/ship/ship.htm

VSA (Very Special Arts) Massachusetts
Maida S. Abrams, President
China Trade Center
2 Boylston Street, Room 211
Boston, MA 02116-9856
(617) 350-7713
E-mail: vsamass@accessexpressed.net

AGE OF ELIGIBILITY

Each state sets eligibility ages for services to children and youth with disabilities. For current information concerning this state, please contact the office listed under "State Department of Education: Special Education."

ABOUT NICHCY STATE RESOURCE SHEETS

NICHCY State Resource Sheets are listings of selected state-wide organizations that can refer people to organizations in their area. We update the state sheets continuously; however, the addresses and telephone numbers of these selected groups are constantly changing. If you find that an address or number has changed or is incorrect, please e-mail us at nichcy@aed.org and let us know. Publication of this document is made possible through Cooperative Agreement#H326N980002 between the Academy for Educational Development and the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizationsimply endorsement by the U.S. Government.

National Information Center for Children and Youth with Disabilities
P.O. Box 1492
Washington, DC 20013-1492
(800) 695-0285 (Voice/TTY)
(202) 884-8200 (Voice/TTY)
(202) 884-8441 (Fax)
E-mail: nichcy@aed.org
Web: www.nichcy.org

Source: National Information Center for Children and Youth with Disabilities, PO Box 1492, Washington, DC 20013 (800) 695-0285 (voice/TTY); www.nichcy.org

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JUNE 1999 FACT SHEET—NUMBER 2

Work Incentives Transition Network (WITN)

Understanding the SSI Work Incentives

The Social Security Administration states that one of its "...highest priorities is to help (recipients) with disabilities achieve a better and more independent lifestyle by helping them to take advantage of employment opportunities." One way that the Social Security Administration supports this goal is by providing benefits called ***work incentives*** that are designed to help individuals enter employment. This brief summary offers information on the most commonly used work incentives which can help those who receive Supplemental Security Income (SSI) to attain and succeed in long term employment.

SSI is a monthly cash benefit that is available from the Social Security Administration to help low income children and adults with disabilities. People who receive SSI also automatically become eligible to receive Medicaid as a source of medical insurance in most states.

The work incentives have been designed to provide the working beneficiary and recipient with the additional income necessary to move toward financial independence. Brief descriptions of some of these incentives follow below. For more information, it is strongly recommended that you identify a knowledgeable advocate who can help you understand your options, and that you contact your local Social Security office.

Earned Income Exclusion

This allows a portion of a person's salary to be excluded when figuring the SSI payment amount. SSI benefits are adjusted only after a certain level of income is reached:

- Up to $85/month of your income has no impact on your SSI check. This is the general income exclusion ($20) and the earned income exclusion ($65) combined. The general income exclusion applies to all income from any source, while the earned income exclusion only applies to income from a job.
- After that, your check is reduced $1 for every $2 you earn. So, if you earn $285 in a month, your check will be reduced by $100. You still come out ahead.

Student Earned Income Exclusion

This allows a person who is under age 22 and regularly attending school to exclude up to $400 of earned income per month: the maximum annual exclusion is $1620. The person must be taking classes at a college or university for at least 8 hours per week; or at a high school for at least 12 hours per week. This exclusion is applied before the general income and earned income exclusions mentioned above.

Blind Work Expense

If a person is on SSI and is blind, expenses needed to earn income that are paid for by the individual (not necessarily related to the disability) can be excluded from the income determination for SSI purposes. Examples of these expenses can include transportation to and from work, federal and state income taxes, union dues, or translation of materials into Braille.

Other Income Reductions

Two additional work incentives allow you to deduct additional money beyond the exclusions mentioned above, under specific circumstances. They are only briefly described here, and are complicated, so you will need to speak to your local Social Security Representative or an advocate for complete details.

- Impairment Related Work Expenses (IRWE). This allows you to deduct from your earnings any disability-related expenses that are necessary to maintaining your job. This might include personal care assistance at work, job coaching services, or special transportation expenses. You cannot use this incentive if you are reimbursed for the expense by another source such as Medicaid.
- Plan for Achieving Self Support (PASS). Under the PASS incentive you can save for or set aside SSI or other income for work goals. The range of possible uses is broad and may include education, vocational training, job coaching services, purchase of adaptive equipment, or health club membership to help with

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Continued Medicaid Eligibility

(often referred to as "section 1619b")

This incentive allows you to keep your Medicaid insurance even if your earnings become too high to continue receiving SSI benefits. If you need Medicaid in order to work, your Medicaid benefits will continue until your annual income is greater than a state threshold level. In 1997 the threshold levels ranged from $12,636 (Arkansas) to $33,039 (Arizona), and was $23,538 in Massachusetts.

Continued Eligibility for SSI Cash Payments

Under Section 1619, a person who is eligible for continued Medicaid coverage under 1619(b) can begin receiving SSI cash payments without reapplying at any time earnings drop below the break-even point (the point at which after deducting your earned income you would receive an SSI payment). This means that even if your SSI check drops to $0 because of your earnings, you can restart it at any time if you lose your job or your income decreases.

Strategies for Managing your Work Incentives

- Always report changes in earnings to your local office. Otherwise, you risk being overpaid or underpaid in your monthly check, and could owe them a refund.
- Remember to make all SSA required reports in writing and keep copies of whatever they provide.
- Confirm your participation in Section 1619a & 1619b, the incentives which allow continued eligibility for SSI and Medicaid. These should be automatic, but are not always. Don't worry! If they mess it up (you'll know if a Medicaid claim is rejected), it can be fixed. Ask for help.
- Locate an advocate who is familiar with SSI and the work incentive programs. Employment programs usually have at least one person with expertise in this area. In particular, a PASS or IRWE must be approved by Social Security. You may find it helpful to get assistance in developing a PASS or IRWE.
- Contact or visit your local Social Security Office and get to know the staff there by name. Recognize that not all Social Security staff understand these programs. Always be willing to ask questions or seek other advice.

For Further Information

Further information about SSI and work incentives is contained in the publication *Red Book On Work Incentives-A Summary Guide to Social Security and Supplemental Income Work Incentives for People with Disabilities.* You can get a copy free from your local office, or by calling the Social Security Administration's toll free number: (800) 772-1213.

Call the Social Security Administration at their toll free number to ask questions or request additional information on any SSI or work incentive topic between 7:00am to 7:00pm on any business day.

The following web sites may also be helpful:

Social Security Administration
www.ssa.gov

WITN
www.wu.edu/rrtcweb/witn/ssi.htm

Center for Psychiatric Rehabilitation
www.bu.edu/sargsych/ssawork.html

Program on Employment and Disability, Cornell University
www.ilr.cornell.edu/ped

The Work Incentives Transition Network (WITN) is a collaborative effort of four projects funded by the Office of Special Education Programs to examine strategies for increasing the use of the SSI work incentives by transition age young adults. The four projects, along with an additional partner funded by the Social Security Administration, include:

Institute for Community Inclusion
Children's Hospital, Boston

Institute on Community Integration
University of Minnesota

Rural Institute on Disability
University of Montana

Rehabilitation Research and Training Center
Virginia Commonwealth University

Employment Support Institute
Virginia Commonwealth University

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ICI
INSTITUTE FOR COMMUNITY INCLUSION

www.childrenshospital.org/ici

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Planning for Employment

What Does This Student Need?	Actions the High School Transition Team May Recommend
ASSESSMENT that identifies current strengths, needs, interests, and preferences for post-school employment, independent living, and post secondary training and/or education	✓ interview youth regarding vocational interests and preferences (use other methods to assess interests and preferences of nonverbal students) ✓ conduct situational assessment (observation in a work setting) to assess endurance, strength, aptitude, social skills, interests, interactions ✓ conduct formal vocational evaluation by a trained evaluator ✓ self-assessment ✓ develop student's awareness of different jobs ✓ discuss health care issues that may impact employment
DEVELOPMENT of job and job placement options and awareness of skills needed	✓ analyze local labor market (contact employment services for state and request information for the region; contact local vocational advisory council; contact local chamber of commerce; review local want ads; contact employment agencies) to identify job openings and local labor needs ✓ get a range of work experiences; explorations, job shadowing, mentoring, and internships ✓ identify community programs offering job placement or training ✓ build network of employer and community program contact ✓ provide training to employers on issues related to employees with disabilities
MATCHING of student and job	✓ analyze the demands and expectations of the job site (e.g., duties, skills requirements, hours, location, transportation, wages, benefits, social skills) ✓ list the support the student needs to be successful on the job ✓ match the student's assessment and the list of needed supports to the job demands, including transportation to the job ✓ identify current gaps and needs for success ✓ identify needed natural supports, job accommodations, adaptive equipment, and support services
School-Work based TRAINING & PREPARATION	✓ provide instruction to youth on job-seeking skills ✓ provide community-based work experiences related to career development ✓ identify potential service providers ✓ provide natural supports and accommodations ✓ provide instruction & training (pre-employment or on-the-job)
PLACEMENT and FOLLOW-UP	✓ work with employer to determine employee's response to the job demands and identify strategies to capitalize on strengths and minimize limitations ✓ provide natural supports and accommodations ✓ monitor progress and readiness for job advancement ✓ monitor changing need for natural supports ✓ make adjustments, as needed

Source: National Information Center for Children and Youth with Disabilities, PO Box 1492, Washington, DC 20013 (800) 695-0285 (voice/TTY); www.nichcy.org

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References and Suggested Readings

✓ - Reading material suited for families

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✓ _____(1998). Eligibility Guidelines for Special Education. MA: Massachusetts Department of Education.

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✓ Copenhaver, J. (1998). What is Section 504 and How Does it Affect My Child's Education? Utah State University Center for Persons with Disabilities, Parent News. 21(4).

✓ De Fur, S. (1999). Transition Planning: A Team Effort. National Information Center for Children and Youth with Disabilities. Washington D.C.

✓ IDEA (Individuals with Disabilities Education Act), P.L. 101-476

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Employment

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Recreation

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Summary of the Laws Related to Adolescent Transition

Americans with Disabilities Act (ADA) P.L. 101-336	Passed in 1990 to supplement civil rights provisions of the Rehabilitation Act, ADA prohibits discrimination against individuals with disabilities. This Act applies to all employers (including state and local government) with 15 or more employees, and protects adults and children with disabilities. Places such as hotels, auditoriums, grocery stores, retail stores, public transportation terminals, museums, parks, schools, and daycare centers are covered by the law.
Individuals with Disabilities Education Act (IDEA) P.L. 101-476	This is the federal special education law. This law requires public schools to offer all eligible children with disabilities a free, appropriate, public education in the least restrictive environment appropriate to their individual needs, through age 21. There is state-to-state variation in eligibility for special education services, but in general, IDEA ensures a child who has a disability that interferes with learning the right to an evaluation to determine if services are needed. In 1997 IDEA was amended to include mandates that transition planning begin by the age of 14 years as part of the individualized education planning for all students in special education. By the age of 16, the IEP must include a statement of needed transition services. This statement focuses on the goals, objectives, activities and services related to transition for students with special health care needs and disabilities, and defines the responsibilities of different agencies and any interagency linkages needed for transition services.
Rehabilitation Act of 1973 (Section 504) P.L. 93-112	This federal legislation protects the civil rights of persons with disabilities in federally assisted or run programs, including health or social programs supported by federal dollars. The law defines a person as disabled if he or she has a mental or physical impairment which substantially limits one or more major life activities. This law attempts to prevent exclusion or restriction from educational programs of students with health impairments and entitles students to special accommodations such as modified assignments or testing situations. Section 504 covers a larger group of students with disabilities than do special education laws.
Massachusetts Chapter 766	This is the Massachusetts state special education law. It is similar to the federal IDEA, but establishes guiding principles for special education specifically for this state.
Job Training Partnership Act (JTPA) P.L. 97-300	The Job Training Partnership Act provides funding for people with disabilities to meet expenses associated with employment. Funds can be used for employment services, training, job search and relocation allowance, and work experience.

The Rehabilitation Act P.L. 102-569

Financial support is provided for vocational rehabilitation through this Act. It is intended to assist persons with disabilities to achieve independence through work and community inclusion.

Technology-Related Assistance for Individuals with Disabilities Act P.L 100-407 and 103-218

This federal law recognizes the need for equipment to help individuals with disabilities perform independently. The law authorizes funding to allow states to create systems of technological assistance.

The Carl D. Perkins Vocational and Applied Technology Education Act P.L. 101-392

This federal law requires that individuals with disabilities be provided vocational education in the least restrictive environment and that they be provided equal access to vocational services including recruitment, enrollment and placement activities.

Massachusetts Chapter 688

This is often referred to as the state's "Turning 22 Law." A certain percentage of more significantly disabled students will continue to need assistance after the age of 22, when Chapter 766 and IDEA no longer apply. Chapter 688 was passed to provide transitional programs for these students before they reach 22 to help them access adult services when they leave the school system. The local education authority must initiate a planning process that will produce an Individual Transition Plan. Services needed, however, are not entitlements, and are subject to appropriation. Many parents are unaware that if a person with a disability has withdrawn from high school or has graduated before reaching the age of 22 they will no longer receive special education services.

Glossary of Terms

Advocate	Term used to describe an individual who is trained to assist families in the development of individualized education plans for their children. There are two types of advocates. (1) Parents may hire a private, independent advocate to support and assist them with the IEP evaluation and appeal process. (2) An Educational Advocate (sometimes referred to as a surrogate parent) may be assigned by the Department of Education to act on behalf of a child when the child's parents are unavailable or have no educational decision-making rights. This person cannot be an employee of any state agency that educates or cares for the child.
Americans with Disabilities Act (ADA)	The ADA (P.L. 101-336) was passed in 1990 to supplement civil rights provisions of the Rehabilitation Act. ADA prohibits discrimination against individuals with disabilities. This Act applies to all employers (including state and local government) with 15 or more employees, and protects adults and children with disabilities. Places such as hotels, auditoriums, grocery stores, retail stores, public transportation terminals, museums, parks, schools, and daycare centers are covered by the law.
Assistive Technology (A.T.)	Refers to assistive technology devices and services. A.T. devices can be simple (velcro, seating systems) or complex (augmentative communication devices). These equipment solutions can improve a student's ability to learn and interact with teachers, family members and friends.
Chapter 766	The Massachusetts state special education law. It is similar to the federal Individuals with Disabilities Education Act (IDEA), but establishes guiding principles for special education specifically for this state. Chapter 766 applies to eligible students with disabilities ages 3 through 21.
Conservatorship	A legal arrangement in which financial oversight is provided for an individual who is able to make non-financial decisions and is not otherwise at risk. If the only finances are monthly benefits, which are handled by a representative payee, then conservatorship is not usually needed.
Evaluations	Tests, assessments, and other critical information about a child that help determine the child's strengths and special needs. An evaluation is done to determine the child's eligibility for special education, and to develop the Individualized Educational Program (IEP).
The Evaluation Team (TEAM)	Includes a child's parent(s), teachers, and other individuals who can help determine what services a child needs to progress effectively in school.
Entitlement	An Entitlement is a legal right. The term is used in reference to Chapter 766, because eligible children and youth are entitled to services and supports written into an Individualized Education Program (IEP). Entitlement programs cannot restrict services to eligible individuals based on funding constraints.

Free Appropriate Public Education (FAPE)	The language used in the federal IDEA to define the right of children with disabilities to publicly funded special education and related services that meet state education standards. The term encompasses preschool, elementary school, and secondary education provided in accordance with an IEP in the least restrictive environment.
Guardianship	Guardianship is indicated when an individual with disabilities is age 18 or older, is unable to make daily personal or financial decisions and is at risk, and where the individual has assets over and above those benefits payable to a representative payee. Full guardianship covers matters pertaining to the person and his finances. Other forms of guardianship are more limited.
Individuals with Disabilities Education Act (IDEA)	The federal special education law. IDEA requires public schools to offer all eligible children with disabilities a free, appropriate, public education in the least restrictive environment appropriate to their individual needs, through age 21. There is state-to-state variation in eligibility for special education services, but in general, IDEA ensures a child who has a disability that interferes with learning the right to an evaluation to determine if services are needed. In 1997 IDEA was amended to include mandates that transition planning begin by the age of 14 years as part of the individualized education planning for all students in special education. By the age of 16, the IEP must include a statement of needed transition services. This statement focuses on the goals, objectives, activities and services related to transition for students with special health care needs and disabilities, and defines the responsibilities of different agencies and any interagency linkages needed for transition services.
Inclusion	The full integration of students with special needs into the regular education setting with typical students. Special education services may be provided in an inclusive setting through individualized adaptation of curricula or classroom activities.
Individualized Education Program (IEP)	A special education service plan for a student in a school program. It is developed by the child's IEP team, and is required for all students receiving special education services. The IEP outlines the student's educational goals, and the services and assistance to which the student is entitled in order to meet those goals. Starting at age 14, the IEP must address transition planning.
Job Accommodation	The modification of a job, job site or work process to make a particular job accessible to a person with disabilities.
Least Restrictive Environment (LRE)	LRE defines the program and placement that assures that a child is educated with children who do not need special education to the maximum extent appropriate, and that special classes or separate schooling are used only when s/he cannot be educated in regular classes even with extra supports and services.
Out Placement	Refers to day or residential placements in private schools that may be necessary for significantly or uniquely disabled children. Services are provided by private contractors to the local education authority, often in partnership with the State Board of Education and other state agencies.

Person Centered Planning	An approach to career or transition planning that focuses on the strengths and interests of the individual.
Personal Care Attendant (PCA)	May be an employee of a home health agency, or may be hired privately by a consumer or family. PCAs assist with activities such as dressing, homemaking duties, eating, bathing, moving from bed to chair, or using the bathroom.
Plan to Achieve Self-Support (PASS)	A type of SSI work incentive. It is designed to help people with disabilities achieve self-support. It allows someone receiving or applying for SSI benefits to put aside a portion of their earned income to accomplish a specific work-related goal, such as tuition for school, or business start-up. The income set aside is not taken into consideration when determining the amount of the individual's SSI benefit. This program is available in all states through Social Security Administration offices.
Post-secondary education	Refers to community college, university and college level programs for students after high school.
Rehabilitation Act of 1973 (Section 504) P.L. 93-112	Federal legislation that protects the civil rights of persons with disabilities in federally assisted or run programs, including health or social programs supported by federal dollars. The law defines a person as disabled if he or she has a mental or physical impairment which substantially limits one or more major life activities. This law attempts to prevent exclusion or restriction from educational programs of students with health impairments and entitles students to special accommodations such as modified assignments or testing situations. Section 504 covers a larger group of students with disabilities than do special education laws.
Related Services	The term used to describe transportation, developmental, corrective and supportive services that are required to assist a child with a disability.
Special Education	Specially designed instruction that meets the unique needs of a child who has been evaluated and found to be eligible. Special education is provided at no cost to parents or guardians.
Supplemental Security Disability Income (SSDI)	A monthly cash benefit to workers with disabilities and their families based on prior contribution to payroll.
Supplemental Security Income (SSI)	A federal program that provides a cash benefit to low income children and adults with disabilities. In Massachusetts, people who receive SSI are eligible for Medicaid.
Supported Employment	Support from an outside agency to an individual in a paid community employment site where the majority of workers do not have disabilities.
Team Meetings (educational)	Held to determine a child's IEP. The program is based on identifying goals, objectives and health care needs. Team members always include family members (or proxies) and school representatives, and may include health care and community service staff.

Transition Services

Defined in IDEA as a "coordinated set of activities for a student, designed within an outcome-oriented process, that promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and community participation." IDEA calls for these activities to be based on the individual student's needs, preferences and interests, and to focus on academic instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and development of daily living skills and functional vocational evaluation. (P.L. 101-476; § 300.27) More generally, transition services may be thought of as including activities in school, community or health care settings which help an adolescent and his or her family achieve greater autonomy and self-management.

Transition Team

Members may include but are not limited to the student, family members, education staff, state agency case managers, occupational therapists, physical therapists, vocational rehabilitation specialists, speech and language pathologists, social workers, college counselors, advocates and friends.

Vocational Assessment

A process to evaluate an individual's strengths, interests and abilities. The process should include assessment of the work, social and cultural environment.

Vocational Rehabilitation Programs

Programs in every state that support people with disabilities, based on eligibility, to outline personal employment goals and become employed. State vocational rehabilitation programs can assign a vocational rehabilitation counselor to assist the individual with disabilities in the employment process.